DOCUMENT RESUME

ED 436 915 EC 307 589

TITLE	Arizona Deafblind Project, 1995-1999. Final Report.
INSTITUTION	Arizona State School for the Deaf and Blind, Tucson.
SPONS AGENCY	Special Education Programs (ED/OSERS), Washington, DC.
PUB DATE	1999-00-00
NOTE	41p.
CONTRACT	H025A50012
PUB TYPE	Reports - Descriptive (141)
EDRS PRICE	MF01/PC02 Plus Postage.
DESCRIPTORS	*Agency Cooperation; Cooperative Programs; *Deaf Blind; Delivery Systems; *Disability Identification; Elementary Secondary Education; Family Involvement; *Family Programs; Inservice Education; Needs Assessment; Postsecondary Education; Public Relations; *Technical Assistance; Training
IDENTIFIERS	*Arizona; Usher Syndrome

ABSTRACT

This final report describes accomplishments of the four-year federally funded Arizona Deafblind Project which attempted to: (1) identify all deafblind children in Arizona; (2) deliver technical assistance to families; (3) deliver technical assistance to service providers; and (4) enhance community oversight, coordination, and collaboration with state and national organizations. Among specific accomplishments were the following: increased awareness throughout Arizona about deafblindness and the Arizona Deafblind Project; implemented two statewide planning meetings to identify needs and set priorities; expanded the membership and role of the project's advisory committee; expanded training activities for early intervention, school age, and transition aged students; identified numerous new students; utilized parents to determine family needs and develop strategies to meet those needs; expanded services for parents and families; expanded training opportunities for parents; initiated Intervener training; systematized and expanded technical assistance activities; expanded the project Loan Library and improved availability of information on deafblindness; developed the project Web site; continued implementation of the Usher Syndrome Screening Project; expanded collaboration with local, state, and national agencies; and secured two specialists in deafblindness. (DB)

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ARIZONA DEAFBLIND PROJECT

FINAL REPORT
1995-1999

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Executive Summary

The purpose of this final report is to summarize progress made on the Arizona Deafblind Project for the complete project period of October 1st 1995 through September 30th 1999. This report will review goals of the Arizona Deafblind Project, provide background to understand accomplishments of the Project, describe activities through which Project goals were accomplished, discuss problems encountered in implementing the Project, and identify how problems were addressed. In addition, OSEP has asked that the report include implications for policy, practice and research, and provide recommendations to OSEP.

The Arizona Deafblind Project made great strides in its service provision over the past four years. Some of its major accomplishments, which will be expanded upon further in this report, are highlighted below:

Major Accomplishments

- Increased awareness throughout Arizona of deafblindness, its impact, and related educational strategies
- Increased awareness of services available through the Deafblind Project
- Implementation of two Statewide Stakeholder Planning Meetings to identify needs and set priorities
- Development of subcommittees to develop strategies to meet needs and work toward solutions
- Expansion of membership and role of the AACDB, the Project's advisory committee
- Expansion of training activities for early intervention, school age, and transition aged students
- Identification of numerous new students
- Utilization of parents to determine family needs and develop strategies to meet those needs
- Expansion of services for parents and families
- Expansion of training opportunities for parents
- Investigation into and initiation of Intervener training
- Systematization and expansion of technical assistance activities
- Expansion of Project Loan Library and availability of information on deafblindness
- Development of Project Web Site
- Continued implementation of Usher Syndrome Screening Project
- Expansion of successful collaboration with local, state, and national agencies
- Securing two Project Specialists trained in deafblindness, even if for only part of the grant cycle

Description of the Project

The purpose underlying the Arizona Deafblind Project service delivery plan is that all infants, toddlers, children, and youth who are deafblind be identified statewide; families be empowered to advocate for their children; and service providers be skilled in meeting the needs of these children. The Deafblind Project was, and continues to be statewide in scope, serving students with dual sensory impairments, their families, and the staff who work with them. Project staff work collaboratively with other state and local agencies to provide them with technical

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assistance, consultation, training, and information so these agencies can provide comprehensive, quality services to individuals who are deafblind.

The Arizona Deafblind Project focused on four goals during the project period:

A. Identification of children who are deafblind.
B. Delivery of technical assistance to families.
C. Delivery of technical assistance to service providers.
D. Enhancement of community oversight, coordination, and collaboration with state and national organizations.

Context Within Which the Project Was Implemented

Arizona is a large state (114,000 square miles) with two major cities, two small cities, and the remainder of the state being either rural or remote. There are three very diverse cultural groups within the state: 1) American Indian, 2) Hispanic, and 3) Anglo American. Each of these cultural groups has quite different values and mores, particularly when it comes to the structure and function of the family, and its role and responsibility within the life of children with disabilities. If cultural issues are not understood and then approached in a culturally appropriate manner, significant obstacles to service provision can be created.

In addition, Arizona's population is one of the fastest growing in the country. Many of the state's schools and communities are finding it difficult to keep up with this growth. For a number of years there has been a shortage of qualified special education teachers throughout the state, even in the two highly populated and popular large cities. Other than Project staff and one university professor, there are not now, nor have there been any teachers in the state trained specifically in the area of deafblindness. This leaves the Deafblind Project to be the bridge between the issues of deafblindness, and the families and service providers within the state.

Furthermore, the communities and school districts in the state of Arizona greatly value local autonomy. For this reason, many local school districts and agencies do not make use of outside assistance or resources, regardless of the positive impact it might have on students and staff. Developing relationships with, and making inroads into these programs, comes at a slow rate. Any change of staff at the local, state, or Project level might put the process back significantly.

Within this context, the Arizona Deafblind Project grant was awarded by OSEP to the Arizona State Schools for the Deaf and the Blind (ASDB). ASDB has been the recipient of this grant for over 20 years, and has the resources through which to administer and assist the Project to grow. The structure of the ASDB agency is advantageous to the provision of services through the grant. At the time of the award, ASDB had a Tucson campus, a Phoenix campus, and the Statewide Services program with three Cooperatives (note that two additional Coops have been added since the beginning of the project period). ASDB Cooperative teachers certified in the areas of vision or hearing provide services directly in schools within local communities throughout the state. Most of the local school districts in the state subscribe to Coop services, although some of the larger urban districts hire staff and provide their own services.

In addition, ASDB is one of the five lead agencies on the Interagency Coordinating Council of the Arizona Early

Intervention Program (AzEIP) to provide Part C services. As a lead agency, ASDB provides services to visually impaired and deaf/hard of hearing infants and toddlers through its Parent Outreach Program (POP). POP staff are in an ideal position to identify dual sensory impaired children since they see virtually every birth to three year old in the state with a single sensory impairment. Project staff work closely with coordinators in the POP program and its affiliate pre-school programs. When children with combined vision and hearing impairments are identified, they are routinely referred to the Deafblind Project.

The sum total of all of these ASDB programs, along with the addition of the Project to Statewide Services, has meant an increase in access for the Deafblind Project. It has given staff of the Project a way to reach most of the children in the state with combined vision and hearing impairments, either through Part C programs, pre-school programs, campus programs, or Cooperative programs located in local schools.

How Goals Of the Project Were Accomplished

Significant progress was made on *all* goals during the four years of the grant through ongoing Project activities coupled with new activities developed to meet needs identified as the Project progressed. Continued input was received throughout the grant cycle from parents, service providers, and advisory committee members, as well as through staff research into current effective practices. Progress on grant activities was greatly increased when the Project was fully staffed with two deafblind specialists and one half time secretary, as it was during the second half of the grant cycle. The difference in operating at full as opposed to half staff was significant, and enabled Project staff to do more than just tread water, but actually offer new and more in-depth opportunities to the state.

The training and experience of said Project staff also made a major difference in services. Individuals with actual background in the field were able to understand the unique impact and needs of deafblindness, and to contribute considerably to training and technical assistance activities. New staff had only to learn about the specifics of Arizona's service delivery systems, its politics, and its strengths and weaknesses. They did not have to acquire the extensive knowledge necessary to understand deafblindness. Working as a team, the two Project Specialists made a dynamic impact on the growth of deafblind services in Arizona.

Goals and Activities

Goal A) Identification of Children who are Deafblind

Three circumstances lead to significantly increased awareness of deafblindness within the state, and the resulting increase in identification of students with dual sensory impairments. First, ASDB reorganized its outreach, cooperative, and deafblind services into a single department called Statewide Services. Subsequently, diagnostic and low vision services were added to the department. As part of the network of Statewide Services, the Deafblind Project began to be recognized and understood more by the teachers it was there to help. Second, for part of the project period, the Deafblind Project had all of its positions filled, which enabled staff to provide much more comprehensive and timely services. Third, but not new, was the close long term relationship between the Deafblind Project and the early childhood outreach services (POP).

Activities for Goal A

Public Awareness and Dissemination of Information to Increase Numbers

In order to identify more infants, toddlers, children, and youth with dual sensory impairments, it was necessary to expand the level of awareness of deafblindness throughout community and service sectors. This was done through:

- provision of awareness presentations (at university courses, workshops, conferences, agencies, meetings, inservice sessions, etc.)
- participation in poster sessions and display tables at conferences and workshops (Az AER, Az CEC, Az TASH, SEA Leadership Institute, transition fairs, Parent Advisor Trainings, etc.)
- development and distribution of new Project brochure
- development and distribution of Deafblind Descriptor Page
- publication of Project newsletters (two + per/year)
- creation and maintenance of Project Web Site
- development and use of Project logo on stationary, brochures, workshop announcements, business cards, mailers, and newsletters to assist with name recognition
- sharing information on state and national resources, and distribution of brochures on projects and agencies serving individuals who are deafblind, including:
  - TAC and NTAC
  - HKNC
  - DB Link
  - Inter Actt Arizona (transition)
  - AZ Early Intervention Program
  - AACDB
  - Hilton Perkins Program
  - NFADB
  - Community Outreach Program for the Deaf
  - Rehabilitation Services Administration
  - Parent Outreach Program
  - ATTDB

Increased numbers of students identified

Entering the grant cycle, the population of deafblind children in Arizona was under-identified. During the project period of 1995-1999, the population of children identified with dual sensory impairments in Arizona grew from 81 to 130 students. This significant 62% increase occurred not only in the birth through two year old population, but also in students of elementary, junior, and senior high school age levels. The growth of numbers was due in large measure to the following activities.

- awareness presentations to AzEIP early intervention providers, ASDB administrators and staff, Special Education Directors, teachers, related services staff, and participants at conferences, workshops, and inservice sessions
- improved early identification through partnership and collaboration with ASDB's Parent Outreach Program and Arizona Early Intervention Program which provide family focused services in natural environments
- expanded partnerships with staff at local and state education agencies who serve the school age population

Deafblind Registry and Annual Child Count

The Project maintained a registry of all children in Arizona identified as deafblind, and completed an annual count of these children. This annual activity was made easier during the project period by the following activities:

- simplified and streamlined child count mailer which goes to special education directors and programs

- developed and distributed a brochure to explain the child count (included in the mailer)
- developed and implemented a new data base system in response to OSEP's changes in reporting categories (new data base allowed information to be electronically tabulated based on queries instead of hand tabulating it)
- worked with staff from the Arizona Department of Education to coordinate and reconcile child count data

The results of using the new child count mailer doubled the response rate, thus lessened the number of follow-up phone calls Project staff had to make to get correct information.

Usher Syndrome Identification

The Statewide Usher Screening Program is a multi-phase project which grew significantly during the project period. It consisted of the implementation of several components, each building upon the ones before it. Variations had to be considered for each agency and site initiating the program. Components included:

- letters of explanation and notification to parents
- distribution and collection of questionnaires to family and staff
- development of an Usher screening data base to sort student information and screening results (must be compatible with each site's computer program)
- collection and categorization of audiological information, questionnaires, and family history records
- entry to data base of audiogram type, questionnaires, and family records
- educational presentations to staff on types of Usher Syndrome, characteristics, emotional and educational impact, and other critical information
- development of local screening procedures specific to site or region
- recruitment and training of staff in each region on screening instruments
- development of procedure to screen and update information on an annual basis
- completion of annual Usher Screening (note: on the Tucson campus this takes four days per school year)

Progress in all ASDB programs was made during the grant cycle. Currently, the Tucson campus has completed all phases of the program, and is in the maintenance phase; Phoenix has their student information collected, and their data base set up; and the Cooperatives are in the planning phase (administrators have participated in an inservice session and planning meeting, and staff of three Coops have received educational presentations on Usher Syndrome).

In addition, the Usher Screening Committee met with Dr. Sandra Davenport for her assistance in problem solving. During her consultation visit, Dr. Davenport presented on Usher Syndrome to ophthalmologists and retinal specialists from Tucson. Both of these activities were done with assistance from NTAC. The educational video tape on Usher Syndrome is in the process of being edited for final production, and will be used for training staff throughout the state.

* ***Obstacles and Challenges Encountered in Meeting Goal A:***

- Many local staff still think that deafblindness means totally deaf and totally blind, not understanding that it can include children with some vision and/or some hearing. This makes it more difficult to identify children with dual sensory impairments. Public awareness activities helped with this, but it is an ongoing issue of educating staff who haven't previously been involved with deafblind children.

- According to statistics, the deafblind population in Arizona is still under-identified. This will become an even greater issue as the population of the state doubles, which it expected to do over the next four year funding cycle.

- Because state census numbers are locally derived, it is difficult to keep track of deafblind children when they move from district to district, or out of state. If numbers were assigned at the SEA, they would follow the child around the state, and it would be much easier to know where a child had moved (note that the SEA has considered doing this). Often parents do not inform the school district where they are moving, and districts don't think to notify the Project of a child's move, even though Project staff remind them to do so. Typically the Project doesn't find out until next child count that a student has moved.

- For the last three years of this grant cycle, the SEA staff responsible for Arizona's December 1 Student Census has changed. Therefore, each year, the expectations of the SEA have changed. This has made coordination with the SEA and reconciliation of the Deafblind Child Count difficult.

- Arizona has elementary, secondary, and unified school districts, each with their own organizational system. When a student moves from an elementary to a secondary district within same town (after child is 13), that district may have different standards for identifying sensory disabilities, thus they may not recognize a dual sensory impairment unless the child is <u>totally</u> deaf and totally blind.

- Even though great strides were made during the grant cycle in educating local staff about deafblindness and the services available through the Project, public awareness continued to be an obstacle. People are unable to identify children if they don't know what deafblindness is. Turnover of staff, growth of the population and teachers to work with them, and hiring untrained staff to fill critical vacancies, all contributed to this problem.

Goal B) **<u>Delivery of Technical Assistance to Families</u>**

The intention of the Project was to make available to families a comprehensive array of services in a coordinated, family centered manner. Throughout the grant cycle, staff made every attempt to provide services in a parent friendly manner, eg., information was translated to native languages, interpreters were provided, and home visits were made during evening hours when families were available. Because staff felt that families under-utilized the services of the Deafblind Project, this area was examined carefully during the project period. In order to help Arizona families understand what services were available to them, many new strategies, delineated below, were identified and tried.

<u>Activities for Goal B</u>

<u>Technical Assistance and Dissemination of Information</u>

As in the past, all requests from families were responded to in a timely manner, and technical assistance was provided upon request or as a need became evident. The availability of technical assistance was publicized in mailings, newsletters, on the web page, in phone calls and meetings, and at workshops and conferences. Parents who received services, whether to attend a conference, have a person centered plan conducted, or to obtain resource information, were asked to write a brief description of their experience to include in Project newsletters so other

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parents could see the wide variety of assistance available. Technical Assistance Request Forms were distributed in some issues of the newsletter, and were available on the web site and at conferences. Parents routinely received all mailings that went out to teachers and agencies, including such items as newsletters, workshop announcements, and legislative alerts. When all was said and done, these methods of making parents aware of and encouraging them to solicit assistance had a nominal impact on the numbers of families who requested help in any way.

Parent Input to Help Serve Families

Project staff were frustrated at the lack of awareness and use of Project services by families. Therefore, Project staff decided to ask parents themselves how to best serve them. Staff invited a parent to attend a Western Region Deafblind Project meeting, sponsored by TRACES, the focus of which was family services. A wide array of activities to meet the needs of families was discussed at the meeting. One successful strategy which several projects were using was to hire parents as staff on deafblind projects.

Because the Arizona Deafblind Project was short one deafblind specialist for the first two years of the grant, it was decided to use some of the vacancy saving to hire a Parent Liaison on a consultative basis. The parent hired was the mother of a transition aged student, thus she was used primarily for the 14-21 age group. Later on, after the Project went through a Site Review, permission was obtained to use vacancy savings on a carry-over basis to hire a second Parent Liaison, who was the mother of a very young child. The idea was to use her to help provide services to families of early intervention and school age children.

Parent-to-Parent Networking

A second method being used around the country to provide appropriate services to families was parent-to-parent networking, which enabled parents to talk directly to other parents who had been through what they were faced with. Understandably, parents could relate to issues about having a child with a disability that most professionals couldn't. To investigate the viability of, and means through which parent-to-parent networking might be facilitated in Arizona, the Parent Liaison and Deafblind Specialist:

- met with Pilot Parent agencies (which received federal parent education monies in Arizona)
- explained about deafblindness, its impact, and project services
- made agreement to offer parent-to-parent services through collaboration with through Pilot Parents and their existing network system
- provided resource information on deafblindness to Pilot Parents for their loan libraries
- sent return postcard mailer to parents of all students on the state Deafblind Registry to determine their interest in participating in the network

The results of the survey were that only two or three parents were interested in participating in a parent-to-parent network. Staff were surprised by this information, and were unsure of the exact reasons why. Many factors could have contributed, such as existing demands on parents, lack of disposable time, misunderstanding of who would pay for phone calls to talk to other parents, or the diverse cultural groups within the state. Because of these results, the parent-to-parent activity was not pursued with the energy initially anticipated. It has not been dropped, but will be investigated again as the Parent Liaisons begin working together in the new grant cycle.

Parent Group Development

Through its HKNC Affiliate program and its Traditionally Under-Served Deaf grant (TUD), the Community Outreach Program for the Deaf in Tucson (COPD) sponsored parent focus groups, and subsequently supported

parents to reach their objectives. One of the identified objectives was to form a group for parents of deafblind individuals. The Deafblind Project collaborated with COPD to support the development of a statewide parent group, which named itself the Statewide Parent Connection. Together, these two agencies:

- encouraged parents to take leadership roles
- assisted the group in developing a return postcard mailer to ascertain which parents were interested in having a parent group, and in what capacity they wanted to participate
- assisted the group to write a proposal to the Hilton Perkins Project soliciting their budgetary assistance (for brochures, mailings, phones, etc.)
- obtained technical assistance from HKNC-TAC to bring a parent speaker in (from successful parent group to share techniques and inspiration)
- helped identify two parents willing to take phone calls at home for the group, and route them to the appropriate parents (one was the Project Parent Liaison who was located in Phoenix, the other was the parent of an adult who was located in Tucson)
- procured a method within their agencies to reimburse parents' phone bills for parent group business

At first the parent group seemed active and enthusiastic. Little by little however, parents stopped coming to meetings, and ultimately the group dissolved. At first, the group consisted almost solely of parents of young adults from the Tucson area. In order to make the group larger, and spread the benefits of parent group membership, parents of students from birth - 22 throughout the state were offered the opportunity to join. Whether this diluted the focus of the group; it became too diverse in age, geographic area, and cultural needs; or it simply could not sustain itself is unknown. What is known is that the needs and situations of the parents in leadership positions changed significantly during this time. Additionally, much larger groups of parents of single sensory impaired students have been unsuccessful in maintaining themselves in Arizona.

Family Service Subcommittee

During the first Statewide Stakeholder Planning Meeting, gaps in services throughout the states were identified and prioritized. Two of the highest priority areas both related to parent and family services. These two issues were collapsed into one. In direct response to this need, a subcommittee for Family Services was formed. This subcommittee has only met a few times, but plans for the future include having the Project Liaisons co-chair the committee, recruit members to serve, determine objectives, and develop a long range plan to guide services to families. Short term action plans and parent feedback will help determine progress of the subcommittee.

Information Packet

In order to provide more comprehensive information to parents upon identification of their child as deafblind, Project staff developed an information packet to send to parents of newly identified students. This packet included: an introductory letter, a parent release of information form, a deafblind descriptor page, common questions and answers about deafblindness, information on the Deafblind Project and the services available through it, a Project brochure, and a form for requesting technical assistance.

The next step will be to have the Parent Liaisons review and suggest modifications to the letters and packet. A parent list serve will be started so that they can work on documents and other projects via the computer.

Parent Advocacy Training

The Pilot Parent organization initiated plans to offer parent advocacy training through Minnesota's "Partnerships

In Policymaking" program. The Parent Liaison (for transition age students) and the Deafblind Specialist served on the advisory committee to implement this program. Partners In Policymaking training occurs over eight months, provides educational and networking opportunities to parents of children with various disabilities, and teaches them strategies to begin grass roots efforts in their local communities. Although no parents of deafblind children were chosen by the Screening Committee to participate in the training, the entire advisory group became more aware of deafblindness. It is hoped that at least one parent of a deafblind child will be chosen if the training is offered again in the future.

Parent Support Groups

As part of their commitment to quality services to families, the ASDB Parent Outreach Program invited Marlyn Minkin to Arizona to provide training to staff in establishing and facilitating parent groups. Ms. Minkin ran several parent groups over the course of the 1998-99 school year, and demonstrated to staff how to facilitate such groups. Some parents of deafblind children were included in the groups, and staff of the Deafblind Project were able to attend all aspects of the trainings. This resulted in the inclusion of deafblind parent groups as an activity for the next grant cycle, but lack of adequate budget necessitated dropping this activity from the 1999-2003 Project. However, parents of deafblind children being served through the Parent Outreach Program will continue to be included in the POP parent groups.

Outside Experts Meeting With Parents

Project staff took advantage of opportunities to have experts in the field share their knowledge with parents. When these consultants were in town for other reasons, such as making presentations, staff sometimes asked them to meet with parents. Examples include:

- when she was in town to present at the Statewide Deafblind Conference, Dr. Barbara McLetchie met with parents of children on the State Deafblind Registry
- when she was in town to meet with the Usher Committee and present to ophthalmologists, Dr. Sandra Davenport met with parents of students with CHARGE Syndrome
- when she was doing feeding consultations in western Arizona, Marcia Dunn-Klein met with parents and providers for inservice

Transition Services

During the Statewide Stakeholder Planning Meetings in 1997, transition did not emerge as one of the top five need areas in the state. This was probably due in part to the strong effort which was being put into increasing transition services up to that point in the grant cycle, and partially due to the specific participants who responded to the invitation to attend the meetings. After the stakeholder meetings, there wasn't as great an emphasis on transition services as before because participants indicated a stronger need for focus on other areas. As a direct result of the stakeholder meetings, subsequent grant activities focused on increasing awareness and training activities. Despite this change in focus from transition services, Project staff were able to offer a number of transition activities to families, mostly during the first two years of the Project. These included:

- sponsored Transition Task Force for parents
- the Parent Liaison and Deafblind Specialist worked together to contact parents to offer transition services
- facilitated Person Centered Planning meetings for transition aged students
- disseminated information to parents regarding transition and the need for planning

- sponsored parents to attend workshops and conferences relating to transition (COHORT, CEC's DCDT)

Responses to Cultural Needs

Because of the great cultural diversity in Arizona, Project staff examined ways of better meeting the needs of Native American families. Not only are values, mores, and communication styles being different, but the logistics of service provision are challenging. For example, when trying to set up home visits or invite parents to attend workshops, Project staff often have to work through local school staff (as many American Indian families don't have phones). Letters may not reach families in a timely manner because mail is often delivered to the Trading Post (many homes are not on mail routes). Using letters is sometimes further complicated because some Native languages (eg.: Navajo) are not written languages, and levels of reading comprehension for English (second language) may be low. Additionally, when attending workshops, Native American parents do not leave their families at home, but bring the extended family with them. This drastically increases the cost of sending parents to workshops.

To find better ways of serving Native American families, Deafblind Project staff looked for specific programs which might have expertise. They found a program called EPICS (Education of Parents of Indian Children With Special Needs) which receives federal funds for parent education of Native American children with disabilities, and whose staff was made up entirely of Native Americans. The Project Specialist, along with the Parent Liaison and a Native American parent from the Pilot Parent organization went to the EPICS offices in New Mexico and met with their staff. EPICS has developed a series of workshops for parents to assist them in negotiating the special education system. If assisted with funding, they are able to provide these workshops to families.

The three individuals who met with the EPICS staff developed recommendations to collaborate to improve services in Arizona. This ultimately resulted in writing a Match Maker Grant to support EPICS training for families. The Match Maker grant was funded for the next project cycle, and will include the services of a Native American Parent Liaison.

Use of TA Evaluations

In the last year of the funding cycle, Project staff began using evaluation forms when technical assistance was provided. Previously, evaluations had been used only for workshops and inservice training presentations. The form is left with parents after consultation or home visits, and they are asked to fill them in and return them in a postage paid envelope. Initial results of these evaluations show that parents are very satisfied with the assistance provided by Project staff. To date, there has been no data base developed to enable staff to enter the number or type of technical assistance requests, or to compile evaluation results and additional needs.

Sent Parents and Family Members to Workshops

The Project sponsored families to attend numerous workshops and conferences both in state and out, including:

- AZ TASH Best Practices Conference
- *HKNC-TAC Parent Conferences*
- AZ Statewide Conferences on Deafblindness
- Hilton Perkins and Project Summer Institutes
- TAC Transition COHORT Workshops
- International Parent to Parent Conference

- National Deafblind Conference
- CEC's International Division of Career Development and Transition Conference (DCDT)
- National CHARGE Conferences
- Washington State Usher Syndrome Family Weekends
- AZ CEC Deafblind Strand
- From Active Learning Workshops on Lilli Nielsen's techniques
- Deafblind Project Summer Institute on van Dijk's techniques

Feedback of Parents

To gain input directly from parents, Project staff informally interviewed some of the parents who had used their services. They wanted to determine why and when parents used the Project, so that staff could understand why their services were under-utilized by other parents. This input could give Project staff potential information regarding how to improve services. It was frustrating for example, to offer services over and over to both schools and families, not be taken up on the offer, and yet find out after the child graduated and aged out that he/she was sitting at home with no job or day program.

The results of this informal survey showed that use of Project services was highly dependent on timing. There was a strong correlation between the family's perceived need, and when the services was offered. When the child is very young, or about to graduate from school, the families may be more likely to accept or seek out assistance. Once the child is settled "for the duration" in a school program, and has the IEP system to guide services, the family tends to rest for a while and not feel a need for additional help. Because parents themselves have limited knowledge of deafblindness, they may not realize that their child's educational program could be better. During school years, parents tend to trust that the teachers and staff serving their child are skilled.

Project staff concluded that to really give parents an awareness of the deafblindness and the variety of services available to them through the Project, that they have to make strong efforts to "catch" families earlier on. Plans are being made regarding how to better utilize the Parent Liaisons upon identification and throughout the school careers of children.

* ***Obstacles and Challenges Encountered in Meeting Goal B:***

- Reaching parents and getting information to them in a manner that was understandable, friendly, inviting, and which encouraged them to utilize the services of the Project was, and is, a challenge. This was compounded by the huge area of the state, its ruralness and remoteness, and the very diverse cultural groups within its population. Different strategies may work for different ethnic groups. Relative closeness to services, as well as the availability of mail, phones, and other forms of technology also effected this issue.

- Project staff felt that it was critical to connect with parents early on in the child's life, for both the parents' sake and the child's, but this was often difficult. Because of all of the infant and toddler services that families receive, adding one more person, especially one which could not provide direct services, was sometimes seen as unimportant or even intrusive. Additionally, early intervention staff often felt protective of the parent who was dealing with grief issues, not wanting to add a second major sensory disability on top of the first. This obstacle has been recognized, and is being addressed within Statewide Services. Plans include having the Parent Liaison and Project Specialist go together with POP staff to a home visit when the child is first identified.

- Under-utilization of Project services by families was a challenge. The needs of parents are different at various times in child's life. Making sure that parents know about services, and then catching them at just the time when they want (or are open to) services is difficult. As delineated, Project staff tried different ways of reaching parents, and will continue to do so. It is hoped that utilizing Parent Liaisons will alleviate some of this problem.

- Families' needs are dynamic and ever changing, and Project staff had to be flexible enough to work with this. Staff could not count on the same parents staying active in organizations like the advisory committee or the parent group. For instance, parents in leadership roles in the parent group lost interest as their child's circumstances changes (ie: one child died, another had to be placed out of the home). Thus those parents who were most active lost interest in leading it. At the same time, other parents didn't necessarily have the energy or interest to run or maintain the group.

  Related to this, finding parents able to be on Arizona Advisory Committee on Deafblindness (AACDB) was a challenge. Most parents had some level of difficulty committing, whether it was because of distance, family obligations, responsibilities to a job, or simply lack of interest.

- Project staff were not sure of the best use of parent liaisons. The Project had not had the opportunity or funds in the past to be able to hire parents to help with services to families. Different strategies were tried, and some met with more success than others. This gave both the Project staff and the liaisons good feedback about what to try in the future.

  Additionally, the liaisons were not full time employees, and their time was limited. Because of this, they were usually available to work just in their own geographic area. The two liaisons were from different areas of the state, thus, finding ways to have them meet, problem solve, and plan was difficult.

- Finding parent liaisons able to effectively serve the diverse cultures in Arizona was a challenge. Staff realized they would need to hire parents of different ethnic backgrounds to serve these families.

Goal C) **Delivery of Technical Assistance to Service Providers**

One of the primary missions of the Deafblind Project was, and is, to have staff in Arizona be skilled in meeting the needs of deafblind students. Throughout the grant cycle, Project staff put a tremendous amount of effort into sharing information about deafblindness, ensuring people knew about the Project, providing training and technical assistance opportunities, and making information accessible to staff at the local level. There were many rewards associated with this effort, but many challenges also existed. Although inroads were made in improving the knowledge and skills of direct service staff, many issues remain as challenges to the Deafblind Project.

Activities for Goal C

Project Site Review

In June of 1996, the Deafblind Project went through a Site Review. Project staff chose Marianne Riggio and Marcia Fankhauser as their reviewers. The Site Review was fair and accurate, and highlighted both the strengths and

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weaknesses of services in Arizona. Some of the recommendations included to:

- conduct an assessment to determine the direction and priorities of the Project through identifying the most critical statewide needs
- identify strategies and develop committees to meet identified needs
- develop a plan to increase public awareness
- develop a clear identify for the Project that is separate from other ASDB services
- define technical assistance which can be offered by the Project
- create a process for accessing Project services
- develop follow-up plans for the technical assistance provided
- offer comprehensive training to individuals who serve deafblind children and determine means to fund trainings
- convene a committee of experts to design content for trainings
- seek input from a small group of parents to identify how to best reach them with our services
- develop subcommittees of the advisory committee to work on specific areas of need

The reviewers confirmed many of the feelings of Project staff, and gave useful recommendations to improve the overall delivery of services in our state. Over the course of the next three years, Project staff utilized the Site Review to help assess our services, and implemented a number of the recommendations generated from it.

Technical Assistance

Throughout the grant cycle, technical assistance was available to all staff serving a child with a dual sensory impairment. TA was routinely offered both verbally and in writing through Project newsletters, brochures, and mailers; at meetings and inservice trainings; in phone calls; on the Project Web Site; and in presentations and display tables at conferences and workshops.

Despite the number of times technical assistance was offered, Project staff still felt most teachers, although they might need some help, were not requesting it. This was perhaps because the teachers still weren't aware of the Project and its services, or perhaps because they were so unfamiliar with deafblindness that they "didn't know what they didn't know." Therefore, to ensure that more direct service staff knew of the TA available to them, a strong emphasis was put on awareness presentations (see Goal A). Staff also developed an information packet to send to teachers of newly identified children, similar to the packet developed for parents. It included a deafblind descriptor page, common questions and answers about deafblindness, information on the Project and the services available through it, a Loan Library Directory, a Project brochure, and a form for requesting technical assistance.

During the grant cycle, the *Technical Assistance Request Form* was revised and made easier to use. Hard copies were distributed in all of the venues listed above, and it was put on the Web Site for people to access electronically. The procedure for delivering technical assistance was also reviewed during the gant cycle. To address issues of local staff not following through with recommendations, Project staff began using an *Action Plan Agreement* to delineate follow-up responsibilities for themselves and program staff.

Finally, staff initiated the use of a *Technical Assistance Evaluation Form* which recipients of the TA were asked to fill out and send in after they had a chance to assimilate information from the visit. To date, there is no data base developed to enable staff to enter the number or type of technical assistance requests, to compile results of evaluations, or to keep track of action plan agreements and progress on them.

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Needs Assessment for Training

Prior to the Site Review, Project staff had organized a committee of professionals with expertise in deafblindness to plan workshops and trainings. This group offered a one day Deafblind Strand at the State CEC Conference. They also developed a basic Needs Assessment Survey for staff to identify their own training needs. The survey was distributed to participants at the CEC Deafblind Strand. Results of the survey were compiled and used as one factor in determining topics for future workshops and summer institutes.

The committee also distributed the newly published deafblind teacher competencies to key staff and administrators throughout Arizona. The competencies were another tool which was used as a guidepost to develop future trainings. In accordance with the site reviewers' recommendations to offer comprehensive training, Project staff requested to use vacancy savings monies as carry over to create a Training Budget. This request was approved, thus allowing a wide variety of training opportunities to be offered to staff and parents throughout the state.

Statewide Stakeholder Meetings

To further identify and prioritize needs related to deafblind services in Arizona, Project staff, in collaboration with key members of the Project's advisory committee (the AACDB), planned and hosted two Statewide Stakeholder Meetings. At the first meeting, gaps in services were listed, categorized, rank ordered, and prioritized. The top five areas of need in the state were identified as:

- Training
- Parent and Family Services
- Continuum of Services
- Adult Services
- Evaluation.

At the second meeting, strategies to meet the needs were identified, and participants volunteered to work in one or more areas, based on their interest and expertise. These groups became ongoing subcommittees, which were formed for four of the five top priorities. Participants in the meetings included parents, teachers, administrators, university staff, deafblind consumers, and state agency personnel committed to deafblindness.

Training Subcommittee

As its first task, the Training Subcommittee identified five levels necessary to provide comprehensive training. These are:

1) awareness
2) general education
3) specific training
4) technical assistance
5) follow-up

When broken down into these five levels, Project staff were able to determine which levels of training had been addressed, and which were still needed. A long range plan was formulated to increase all levels of knowledge to staff across the state. The Training Subcommittee continued to meet throughout the grant cycle, and helped guide the training efforts of the Project.

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Continuum of Services Subcommittee

As a result of the priorities set at the Statewide Stakeholder Meetings, a Continuum of Services Subcommittee was formed to facilitate better carryover between school providers with each other, and between the school and home settings. The first activity of this subcommittee was to ascertain names and positions of all team members serving each student in the state. This was done by sending a questionnaire to the parents and to the school program asking for the names and addresses of the staff. Subsequently, the committee developed and distributed to the team members, a questionnaire asking for specifics of the child's program. Responses of the different team members showed the consistency with which they viewed the child's educational program and communication mode.

The initial response rate to the surveys was poor, and even with several follow-up phone call, the response rate did not improve. This may have been in part to the lack of clarity of the purpose of the survey. For example, when asked about how the student was communicated with, many staff wrote, "ask the communication specialist." A clearer introductory paragraph might have helped alleviate this response, and might have given them the information they were seeking. This subcommittee will be reassessing its direction during the upcoming grant cycle.

Workshops and Conferences

Numerous opportunities to attend workshops and conferences were provided to staff throughout the four years of the grant cycle. Frequently these were planned and sponsored collaboratively with other agencies or members of the AACDB. The Training Budget, created from vacancy savings, enabled the Project to provide these workshops or to send local staff out of state to attend pertinent trainings. Without these funds, none of the workshops or conferences could have occurred. Some of the training opportunities during the four years of the grant included:

Workshops planned and sponsored or co-sponsored by the Project:

- Deafblind Statewide Conferences
- Deafblind Strand at AZ CEC
- Local Team Trainings
- Deafblind Parent Advisor Training
- Advanced Parent Advisor Trainings
- Active Learning Workshops
- Van Dijk Summer Institute

Workshops to which Project sent local staff, both out of state and in state:

- AZ TASH Best Practices
- National Deafblind Conference
- Communication Specialists on Deafblind TEAMs to see Jan van Dijk
- Early Intervention specialists to Lilli Nielsen
- Local or state transition team members to TAC COHORT Workshops
- Local district and Cooperative staff to Hilton Perkins Summer Institute
- Local and State Team members to HKNC Transition Workshop
- TAC COHORT Workshops

Active Learning Training

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Because children with dual sensory impairments are frequently very passive and non-motivated, Project staff were intrigued by the work of Dr. Lilli Nielsen who developed many strategies to encourage active learning. She had been very successful in showing that through their activity in a safe and predictable environment, children could become motivated to learn about the world, and were able to remember, compare, and plan.

In the spring of 1998, the Project sent its own two specialists plus eight staff from around the state to attend a three day workshop with Dr. Nielsen. The intention was to develop a CADRE of staff with training in Active Learning techniques. The three day training was quite disappointing, and many staff felt that they had not learned how to use the strategies. However, some staff were excited by the ideas, and were in contact with Kathee Keller, from the Washington State Deafblind Project, who had been successfully using the methods. That summer, with consultation from Kathee, a pilot project to test some of the techniques of active learning was initiated with two preschool students. Immediate results were seen in both students.

Subsequent to this, two workshops (1998 and 1999) were provided to share these strategies. The workshops were offered to teams serving children of all ages, but were geared specifically to early childhood and preschool staff. Kathee Keller presented at both workshops, with assistance from the four staff who had participated in the pilot project. Follow-up is being conducted with participants from all of the trainings, and staff will be able to participate in the Active Learning web site that the Washington State Deafblind Project is setting up.

Transition to Post School Environments

During the first two years of the grant cycle, there was a strong emphasis on transition services. However, as stated in Goal B, during the second two years, the focus of grant activities changed, and more emphasis was put on public awareness and training activities. Project staff were not the only key transition players whose focus changed during this time frame. Other critical members of the Arizona Transition Team on Deafblindness (ATTDB) had similar situations. For example, the federal grant in transition ended and SEA staff had new responsibilities other than transition; the RSA staff had major responsibilities added to her role (thus decreasing the time she could commit); and the COPD staff became the head of her agency, and had to focus on administrative responsibilities and fund raising activities.

Despite this deceleration in transition activities, Project staff continued to make accomplishments in this area. Over the four years of the grant, the Project Specialist:

- provided consultations for students transitioning from high school to adult life
- participated in Local Teams to facilitate transition for individual students
- collaborated with state and local agencies by attending monthly local team meetings and providing training
- was active in and presented at SEA Transition Leadership Institutes and Project ACTT trainings
- participated in Pima County COALITION
- participated in several Transition Fairs around the state

The Project Specialist also maintained an active leadership role in the Arizona Transition Team on Deafblindness (ATTDB) for the first two years, which:

- sponsored two Local Team Training workshops
- sponsored a Parent Task Force on Transition
- participated in TAC COHORT Workshops
- had regular State Team meetings

Adult Services Subcommittee

As a direct result of the Statewide Stakeholder Planning Meetings, the Adult Services Subcommittee was formed. The Project Specialist for 14-21 year olds participated in this committee in order to facilitate better transitions between school and adult agencies. The primary goals of this committee were to make transitions smoother, and to re-create the Adult Deafblind Registry which was lost after an RSA staff member left the state. The committee initiated a procedure to gain permission from parents of graduating students to refer them on to state and national agencies including Vocational Rehabilitation, Community Outreach Program for the Deaf, Valley Center of the Deaf, the Tucson Association for the Blind, and HKNC.

The committee also met with HKNC representatives and got their input on data necessary to include on the Adult Registry. HKNC had recently developed a simplified version, which may be useful to Arizona in setting up its data base. Obstacles facing the development of an Adult Registry included:

- who would pay to have the data base developed (none of the agencies has the expertise in-house or the funds to hire out)
- where would the data base be housed
- which agency would maintain the records and update the entries

The possibility exists that the data base used by the Deafblind Project for its Student Registry could be used as is, or be modified for the Adult Registry. This is currently being explored.

Dissemination of Information

Dissemination and sharing of information related to deafblindness and Project activities is an important activity of any deafblind project. During the grant cycle, the Arizona Deafblind Project routinely disseminated information through a variety of activities. As stated earlier, Project staff were frustrated that much of this information was not getting to the front line staff who worked with the students, as it seemed to stop at the administrators' desks.

A list of teachers serving students with deafblindness and severe disabilities did not exist in the state. Therefore, Project staff revised the Student Profile Sheet for the annual Child Count to include the name and address of the primary teachers. They also modified the data base for the Deafblind Registry to incorporate this information. Currently, all teachers of students on the State Registry receive all mailings. Mailing lists werealso built up through the dissemination of postcards on which anyone could sign up to be added to the mailing list. These are distributed at all presentations, workshops, consultation visits, meetings, display tables, and in other venues. Use of the postcards has added about 150 additional interested people to the Project mailing list.

Information about the project is distributed to these people through:

- newsletters (at least two per year)
- workshop announcements
- mass mailings (ie: Deafblind Descriptor page, Project brochures, legislative updates...)
- distribution of information and brochures on agencies related to deafblindness (HKNC, DB Link, TAC and NTAC, COPD, RSA, etc.)

Project Web Site

A Project Web Site was developed during this grant cycle. As time goes on, and as needs dictate, new pages will

be added. Current pages on the site are:

About the Arizona Deafblind Project (Home Page)
What is Deafblindness
Deafblind Fact Sheet
Causes/Etiologies
About Project Staff
Links and Resources
Request Technical Assistance
Feedback

Project Loan Library

Much effort went into expanding and reorganizing the *Project Loan Library*. The Loan Library Directory went through a few major revisions, and was put on a data base. The data base has had several bugs, and is not being used yet. Once it is up and running, staff hope to be able to use it to call up items due back in, mail reminders, tally numbers of items borrowed, etc. The Loan Library Directory will also put on the Web Site so both parents and staff can request items electronically.

Consultations by Outside Experts

In addition to providing technical assistance and training themselves, Project staff also made use of outside experts to consult to local programs. These included:

- Marcia Dunn Klein for feeding inservice and evaluations
- June Downing for person centered planning and IEP development
- Stephanie MacFarland for VISTA Teaming, van Dijk strategies, and communication
- Rustie Rothstein (HKNC representative) for Usher Syndrome and technology

TEAM: Transdisciplinary Education Assessment Model

One of the activities carried on from the previous funding cycle was the continuation of the Transdisciplinary Assessment Education Model team evaluation process (TEAM). During this grant cycle, some activities related to the TEAM process included:

- established second team in the Phoenix area (trained by the Tucson team)
- developed awareness presentation and delivered it to LEAs
- completed four evaluations of students in local schools
- completed follow-up TA in to staff and families in two local districts

Became Internship Host Site

Project staff felt that a key component to building and maintaining deafblind services throughout the country is the training of university level students in the activities of federally funded deafblind projects. To that end, during the last three years of the grant cycle, the Project worked with three graduate level interns to provide an administrative internship in the area of deafblindness. One was a PhD candidate from the University of Arizona, and two were Masters level students from Boston College. During this time, an agreement was made with the Boston College Deafblind Teacher Training Program to continue acting as an training site.

Maintained Skills and Knowledge of Project Staff

Recognizing the importance of keeping up to date with effective practices and research related to deafblindness, Project staff continued to update their own information and skills. They:

- made use of the services of DB Link, the internet, and deafblind list serves
- participated in regional deafblind meetings and trainings hosted by TAC and NTAC
- networked with university staff and peers on other deafblind projects

- read journals and pertinent articles
- attended state and national conferences, and brought information back to their state, including:

    - Infant Attachment
    - AZ TASH
    - Social Role Valorization
    - CEC International DCDT
    - AZ AER
    - NTAC meetings/workshops
    - TRACES Evaluation Workshop
    - Statewide Services Annual Workshops
    - AER Transition Workshop
    - Navajo Philosophy

Worked Toward Systems Change

Despite all of the efforts of state and local personnel, direct service staff, and Deafblind Project staff, many deafblind children in Arizona were still not receiving consistent, high quality programs from staff skilled in dual sensory impairments. To identify ways to address this concern, Project staff talked to peers in other states, read literature on effective practices, and began identifying models and strategies which did seem to make a major difference in the skill development of deafblind children, and which could make an impact on the system serving the children. The active learning strategies of Lilli Nielsen were one way to offer such opportunities early on.

A second way, which had made a profound difference to deafblind infants and toddlers in Utah, was the use of interveners for ten hours a week with each child. Utah was able to show significant benefits of using interveners, and even obtained funding from their state legislature to implement intervener services for deafblind children. Further research into this model lead Project staff to implement it with one child. The Division of Developmental Disabilities funded a one on one personal living skills provider, for up to forty hours a month. Dr. Stephanie MacFarland recommended a graduate student with good knowledge of van Dijk's techniques. Once this individual began working with the child, his gains in cognitive, communication, and motor skills were astounding.

This single success, coupled with discussions of peers in other states, led Project staff to include intervener training in their new grant. In August of 1999, a meeting was held with administrators from ASDB agencies throughout the state to educate them on the purpose and roles of interveners. The meeting was so successful, that the first Intervener CORE Training in the fall of 1999, taught by Linda Alsop of the SKI*HI Institute, drew 77 participants. Fifteen para-professionals who worked with deafblind students (either one to one or two to one) were identified to continue with the remaining phases of the Intervener Training. The trainings will be repeated each year of the next grant cycle. Eight individuals were chosen to continue the training and become state trainers.

It is hoped that the skills of the deafblind children receiving intervener services will significantly increase, and that local districts will recognize the value of interveners and commit to providing these important services. As parents see the difference an intervener can have in their child's life, they too can play a key role in advocating funding for intervener services. Dr. Stephanie MacFarland from the University of Arizona is partnering with Project staff to become a trainer. Together they will be able to incorporate this effective practice into training programs so that it becomes part of the teacher training philosophy. It is a slow road to any type of systems change. It may take many years to incorporate the philosophy, use, and funds to hire and train interveners, but this is a first step.

* ***Obstacles and Challenges Encountered in Meeting Goal C:***

- Information about deafblindness and the Deafblind Project was not reaching direct service staff. Newsletters, workshop announcements, and child count information seemed to stop at the administrators desk. The majority of teachers and direct service staff did not have the expertise to serve deafblind students appropriately, and to offer them a rich learning environment. Often they didn't know of the existence of the Deafblind Project and its services, and thus didn't ask for assistance. Many were highly qualified people in their own fields, but they did not necessarily realize how much they didn't know about deafblindness.

- Especially at the beginning of the grant cycle, there was an overall lack of understanding in Arizona about deafblindness and the wide range of combined vision and hearing losses possible. Students were recognized as having only a vision or a hearing loss, not a dual loss. Coupled with this, administrators at the local level were often reported to say that their staff had the necessary skills to serve the student, even if he/she was identified as deafblind. Neither the administrators nor the staff understood the tremendous impact a combined vision and hearing loss could have on the student's learning and communication.

- Training and technical assistance can only be provided with adequate funding. The Project entered the grant cycle with no training budget written into the grant, thus had planned no large scale training activities. Technical assistance was done on a program by program basis, which is time consuming at best when attempting to train all service providers separately.

  Large scale workshops could give a basic level of understanding to a large number of people, with TA following. The ability to use vacancy savings to incorporate a training budget was a critical. Clearly, many training activities were delivered that would not have been if these monies had not been available. The workshops and conferences added greatly to the expansion of knowledge in the state.

  During the grant cycle, Project staff were only partially successful in finding state money to support training efforts for this low incidence population. The Community Outreach Program for the Deaf and the Rehabilitation Services Administration were always willing to help plan and sponsor training activities. Both agencies collaborated to cover interpreter costs at the trainings, and RSA was occasionally able to help with presenters fees. However, neither agency had large amounts of money to contribute to joint training. Project staff are working on developing a closer relationships with the director of the SEA's CSPD (who has recently joined the Project's advisory committee).

- Staff turnover throughout the state at all levels, particularly the local level, presented a host of problems. Frequent changes in local staff make it impossible to keep up with needs of all children and all staff. For example, for one student, members of his educational team changed every year, and sometimes within the school year. Thus, no matter how much time and energy Project staff spent on training and TA, they had to start all over again with each new group. It was not a simple matter to provide hands on TA to this program, as it was nine hours away on the Navajo Reservation. As with many deafblind children, consistency among staff, and between staff and home was negligible, and the student suffered for it.

  Turnover at the state level impacted relationships with these agencies. Project staff must cultivate each relationship so that the state staff member understands deafblindness and develops a commitment to it.

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When these staff members change, as they did frequently at the SEA during this grant cycle, Project staff must begin the process again.

- Added to this mix is turnover of Project staff. One Project Specialist position was not filled for first two years of the grant cycle, and this position has been vacant again since August 1999 (although someone has been hired to begin in March of 2000). Each time the position is vacant, one person has to take over the responsibilities of two people, thus spreading that person very thin. Once on board, it takes at least a full year for a new staff member to become really comfortable with a position, and much longer to understand a complex state and local system such as Arizona's.

  The Project has been fortunate that both individuals hired to fill this vacancy (1997and 2000) have Masters degrees in Deafblindness, bringing their expertise and knowledge with them. Because of the scarcity of people trained in deafblindness, deafblind projects are often in a position where they must hire staff who have advanced degrees in vision, hearing, or severe disabilities. Just like LEA staff, these individuals, who are supposed to be the experts to help everyone else, have to pick up skills in deafblindness.

- The lack of methods to easily collect and tally data was a long term obstacle, which still has not been alleviated. Data related to numbers and types of TA requests, evaluations, resources provided, training, state needs, student outcomes, etc. all must be developed and maintained. Someone with expertise in the development of documentation procedures and data bases is necessary. The Project is able to utilize Statewide Services' computer staff person, but he too is responsible for meeting the needs of a huge statewide department (600+ people).

  Related to this, the Project secretary, who would be responsible for entering much of the data only works half time. For the next funding cycle, Project staff wrote the secretarial position in as a full time, but it had to be cut back to half time again when final monies were negotiated.

Goal D) <u>Enhancement of Community Oversight, Coordination, and Collaboration with State and National Organizations</u>

The intention of this goal was to utilize feedback from consumers to improve overall services in the state of Arizona to deafblind children, their families, and staff who worked with them, and to work collaboratively with state and local agencies to provide these services. Over the four years of the grant cycle, Project staff solicited input from parents, consumers, and professionals in the state. Their valuable feedback assisted the Project to improve and expand services. Awareness, training, technical assistance, and planning activities were all enhanced by the use of information from these consumers. Many of the specific collaborative activities used to gain input have been elaborated on previously in this report (eg., Statewide Stakeholder Meetings, sub-committees, Project Site Review, Needs Assessment Questionnaires, ATTDB, Pilot Parents, jointly sponsored conferences and workshops, etc.), and will not be repeated here.

<u>Activities</u>

<u>In-State Collaboration and Coordination</u>

The Arizona Deafblind Project has a long history of working collaboratively with state and local agencies. Because Arizona is not a highly funded state in any of the human service areas, agencies have found it mutually beneficial

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to work together to provide training and services, particularly for low incidence populations. By planning and sponsoring activities together, the resources of each concerned agency were maximized, and re-inventing the wheel was avoided.

Arizona Advisory Committee on Deafblindness

The Arizona Advisory Committee on Deafblindness (AACDB) has been in existence for over 15 years. It is made up of a core group of very committed individuals representing various agencies committed to deafblind services. By mutual agreement, it serves not only as the advisory group for the Arizona Deafblind Project, but also in an advisory capacity to all of the projects in the state which receive federal monies toward deafblindness. In this way, the agencies can support each other, be kept abreast of activities in the state, and work togther toward a common goal.

Most of the key agencies involved in deafblind services in Arizona are represented on the AACDB. These include:

- Az Department of Education
- Az Division of Developmental Disabilities
- University of Arizona
- Az Rehabilitation Services Administration
- Community Outreach Program for the Deaf
- local education agencies

During this Project period, there has been a significant effort to expand the AACDB membership to include more parents, individuals who are deafblind themselves, and new Department of Education and DDD staff. Four parents began to serve on the advisory committee, two deafblind consumers, and the Director of CSPD/SIG from the Department of Education.

Several subcommittees to the AACDB were formed during this grant cycle. The AACDB and its subcommittees sponsor or support many of the collaborative activities of the Project, such as Statewide Conferences, development of Deafblind Descriptor page, return postcard mailers, etc. The AACDB meets 3-4 times a year, and its subcommittees meet in-between.

National Resources

Project staff also maintained strong working relationships with national organizations to enhance quality services for individuals who are deafblind. By building strong partnerships with these agencies, services can be provided which the Deafblind Project could not provide on its own. These agencies included:

- DB Link
- TAC
- TRACES
- NTAC
- HKNC Regional Representatives
- HKNC National Training Team
- Hilton Perkins Project

ASDB Deafblind Committee

Early on in the grant cycle, staff at ASDB, Tucson campus, convened a committee to determine if the educational needs of its deafblind students were being appropriately met. The Deafblind Project staff were active in this committee, and participated in meetings and surveys. The Project Director facilitated a site visit and campus evaluation from the Hilton Perkins Project. Results of this visit included recommendations by Hilton Perkins staff,

and a commitment by them to work with ASDB programs, in collaboration with the Deafblind Project and the University of Arizona to upgrade overall programs in the state.

Self Evaluation

Throughout the four years of the grant, the Project utilized several activities to maintain an ongoing system of self evaluation and feedback. These included the Project Site Review, the Statewide Stakeholder Meetings, Needs Assessment Surveys, workshop evaluations, technical assistance evaluations, input from the AACDB and its subcommittees, input from the ATTDB, and feedback from the field. Project staff examined national census data to determine incidence statistics, Deafblind Teacher Competencies to compare skills, and research on effective practices for family and educational services.

All of this information gave Project staff ongoing feedback to help evaluate our services and set new directions. It was considered a very comprehensive way to gather information.

Obstacles and Challenges Encountered in Meeting Goal D:

Very few obstacles were encountered in meeting this goal. By the very nature of the funding structures in Arizona, agencies engage in cooperative relationships to in order to maximize their resources and provide more comprehensive services. The few obstacles that were identified were:

- The changing roles and responsibilities of key members of the AACDB and ATTDB sometimes meant a person couldn't spend the same level of time on deafblind related committees and projects as in the past. This did happen in the last two years of the grant, but, for the most part, it is a cyclical occurrence, and will pass.
- Another obstacle which was already mentioned, was the lack of equity in funding for joint projects. Throughout the funding cycle, and most probably in the future also, the Deafblind Project was in the best position to expend funds for joint activities.
- As mentioned, finding and educating people to replace state agency staff on the advisory committee (AACDB) was an obstacle. Finding parents for this advisory group was also an ongoing challenge.

Problems, Solutions, and Lessons Learned In Implementation of the Project

Most of the problems, solutions, and lessons learned have been identified throughout the course of this report. A few that have not been highlighted, most of which will pertain to deafblind projects around the country, include:

- The great difficulty in finding and attracting Project staff trained in the area of deafblindness. There are too many positions for too few recruits. There are not enough teacher training programs, and those which do exist, do not train enough people. Some of the people who complete a teacher training program don't stay in, or even enter the field. Others remain in their own part of the country, leaving some regions with the difficulty of getting people to move to their part of the country.

- At the local level, there is also difficulty finding and recruiting teachers and early intervention staff, especially for rural and remote regions of the state. This problem can be expected to increase as the population in the western states increases.

- There is not enough project staff to cover such a huge and diverse state. Project staff sometimes feel that they are only making a dent in meeting the needs of the state. In addition, the Project budget will only support a half time secretary.

- There is difficulty in finding the time or funding on the Project to establish documentation procedures, especially those which are easy to use. This is due to the shortage of funds to hire our own consultant to create data bases, lack of Project staff expertise to do this themselves, and lack of secretarial hours to enter the data.

Recommendations for OSEP and Implications for Policy, Practice, and Research

Staff of the Arizona Deafblind Project would like to take this opportunity to thank OSEP for its support in funding and maintaining deafblind projects. Without this funding, deafblind children across the country would not be receiving appropriate services, nor would their staff have the training and technical assistance needed. Although it is sometimes discouraging and the obstacles seem insurmountable, staff also recognize the great help their services are to families, teachers, and children. Suggestions for OSEP include:

1) Since data and documentation are a major component of federally funded db projects,we recommend that OSEP develop ways to help Projects implement sensible, easy documentation procedures. This could be done by asking NTAC to develop guidelines or procedures, and make them available to all projects (as was done for the child count). Given the limited amount of funds, it would make more sense for an agency such as NTAC to provide this service for all of the projects. In this way, each deaflbind project will not have to reinvent the wheel.

This would facilitate the collection of similar information by all projects. If made available in different formats, all deafblind projects could adapt the data bases to their own system, or even add to them for the collection of information specific to that state. Data bases should include GPRA performance measures, as well as key information needed by projects.

2) OSEP should continue to support research on strategies and techniques that have proven extremely successful for individuals with deafblindness. There should also be ways to share this information among states (web sites, list serves, additions to DB Link, conferences), and facilitate learning and application of these techniques within states. If web pages were developed, of course it would be necessary to support individuals to maintain the sites. These strategies might include:

- the theories and methods of van Dijk
- the Intervener Model
- Active Learning strategies
- Hand Under Hand techniques

3) The importance of maintaining these funds for state deafblind projects cannot be over-emphasized. The hope

is always for an increase in funds to strengthen and expand training and technical assistance within states.

4) Expand the number of teacher training programs in deafblindness. Don't think that deafblind children can be served by teachers without training in this area. Although they come with their own expertise, teachers trained in vision, hearing, or severe disabilities do not have the understanding of the impact of a dual sensory impairment, or of the strategies most successful with deafblind children.

5) Continue funding DB Link. This is an invaluable resource to state and local staff both.

6) Add funds for a technology resource along the lines of DB Link, but with one or more staff who are experts in all of the technology able to be adapted for use by deafblind persons. The availability grows on a daily basis, and it is impossible for most people to keep up with it.